LEGISLATIVE SERVICES AGENCY
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FISCAL IMPACT STATEMENT

LS 6870
BILL NUMBER: HB 1329

NOTE PREPARED: Jan 13, 2015
BILL AMENDED:

SUBJECT: Sickle Cell Disease Grant Program.

FIRST AUTHOR: Rep. Porter
FIRST SPONSOR:

BILL STATUS: As Introduced

FUNDS AFFECTED: X **GENERAL**
DEDICATED
FEDERAL

IMPACT: State

Summary of Legislation: This bill adds specific requirements to the sickle cell program of the Indiana State Department of Health (ISDH). The bill requires the ISDH to establish sickle cell disease centers in various regions of Indiana.

Effective Date: July 1, 2015.

Explanation of State Expenditures: *Summary*: The maximum annual costs to fund the Sickle Cell Disease (SCD) Grant Program are estimated to be approximately $22.1 M. Actual costs will depend on grants administered by the ISDH for medical costs associated with treating sickle cell disease.

The ISDH currently provides statewide-contracted follow-up services and genetic counseling resources to individuals living with SCD at an annual cost of $360,000. To the extent these current services will meet the requirements of the bill, including the requirements to operate regional sickle cell disease centers, ISDH expenditures and/or workload to fulfill the bill's requirements could be reduced.

The bill's requirements represent an additional workload and/or expenditure on the agency but to some extent may be within the agency's current functions. Existing staffing and resource levels if currently being used to capacity may be insufficient for full implementation. The additional funds and resources required could be supplied through existing staff and resources currently being used in another program or with new appropriations. Ultimately, the source of funds and resources required to satisfy the requirements of this bill will depend on legislative and administrative actions.

Additional Information: There are an estimated 1,600 individuals in the state who have SCD. Based on mortality data for individuals with SCD, it is expected that most of the 1,600 individuals are under 18 years of age. Additionally, SCD primarily affects individuals of African-American and Hispanic heritage.

The average annual costs for treating a child with SCD are estimated to be $14,150 under the Medicaid program and $17,900 under employer-provided insurance. The estimated costs to provide similar services to an adult with SCD are estimated to be $28,300 under the Medicaid program and $35,800 under employer-provided insurance.

Based on state poverty rates by race and ethnicity, between 368 and 432 individuals with SCD are expected to be eligible for treatments funded by Medicaid. The remaining 1,168 to 1,232 could receive grants under the bill's program. If all non-Medicaid-eligible individuals with SCD receive between $14,000 and $18,000 in grants per year for the costs of SCD medical care, state expenditures are estimated to be between $16.5 M and $22.1 M per year. These estimates would most likely be maximum state costs, as it is unknown how much in treatment costs for these individuals are required, but unfunded.

The ISDH currently provides newborn screening for SCD (and many other diseases) for 88,000 annual births as part of the Newborn Screening Program. The ISDH reports that most individuals who have SCD today would have received a screening test and are aware of their diagnosis. In instances where an individual has not received a screening test for SCD, Medicaid finances the costs of SCD testing in infants, children, adolescents, and adults.

Explanation of State Revenues:

Explanation of Local Expenditures:

Explanation of Local Revenues:

State Agencies Affected: ISDH.

Local Agencies Affected:

Information Sources: U.S. Centers for Disease Control; Kaiser Family Foundation; ISDH; Hassell, Kathryn, *Population Estimates of Sickle Cell Disease in the U.S.*, American Journal of Preventive Medicine 2010, 38 (4S):S512-S521; Joey Fox, ISDH.

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